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ABSTRACT

This presentation describes research on families with mentally retarded children, focusing on trends since 1983, the year that family research issues were reconceptualized in a paper titled "A Model of Stress, Coping, and Family Ecology" by Keith Crnic and others. The trend analysis concentrates on four issues: (1) the magnitude of the impact of the child's disability on the family and the resiliency of the family; (2) the increasing level of sophistication and perception concerning the multidimensional mechanisms that account for variation in how families respond to mental retardation; (3) the level of knowledge of how parents and families react, cope, and find resources during the first 5 years of the lives of their disabled children, compared to knowledge of the next 40 or 50 years; and (4) use of the mother as the primary family informant, especially mothers who are white middle class. The paper concludes that professionals need to identify the degree of fulfillment and personal growth that new parents get from their parental experiences, rather than always measuring strains and burdens. (JDD)

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THEORETICAL ISSUES IN FAMILY RESEARCH

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Theoretical Issues in Family Research

Interest in how families are affected by the experience of having a child with a disability has been evident for decades. In a seminal paper published in AJMR in 1983, Keith Crnic and colleagues reviewed the results of hundreds of studies conducted over a thirty year period. They characterized the research as based on a pathological model of family functioning. Let me quote from their review:

> No succinct model presently exists through which one can develop an empirical understanding of families of retarded children. Rather, investigators have seemed to rally around the concept of anticipated pathology in these families. Pathological adaptations are generally assumed to be a function of stress associated with the presence of a retarded child and have led to the development of a stress-reaction hypothesis to explain maladaptive family functioning.

They then proposed a highly influential, reconceptualization of the issues important for family research. Their model was called "A Model of Stress, Coping, and Family Ecology." It emphasized the need to account for individual differences in families and the need to specify the factors that mediate family adaptation. They pointed directly to differences in family coping strategies for managing stressful situations and to

differences in the family ecology--its access to support, services, and professionals--as critical factors that may account for why some families cope well and some less well with the experience of parenting a child with a disability. While this model and the factors it points to have certainly gained widespread acceptance in 1991, their analysis is often credited with recasting and reinvigorating family research in 1983.

For this morning, I'd like to describe some of the trends in family research since 1983. Has the field really changed? What issues have been investigated and what new ones are on the horizon? Are we any farther along in developing useful theoretical models of family adaptation?

Let me concentrate on four issues. First, what have learned about the magnitude of family impacts and about the resiliency of families? The results of several studies reported over the last decade suggest that we need to re-evaluate our prevailing basic assumption that mental retardation causes an explosive, damaging, and enduring negative reaction among all families. While no one discounts the fact that the diagnostic period is an extremely stressful one for families, there is increasing evidence that the crisis is less lengthy than previously thought, and that family coping and resources "kick in" to help families equilibrate.

Last year at this conference, I described results from our research on 152 families entering early intervention programs in Massachusetts and New Hampshire. I noted that we found that the majority of families <u>did not report</u> atypically high levels of

parenting stress, depression, social isolation, or restricted family relationships either upon entry into the service system or one year later.

A longitudinal study by Gowen, Applebaum and colleagues, reported in the 1989 special issue on family research of the AJMR, compared mothers of children with and without disabilities and found no differences between these two groups of mothers in the level of maternal depression and feelings of parenting competence.

Lynn Wikler's research suggests that there is an ebb and flow to family's reactions, with some predictable stages presenting more difficulties for families than others. The concept of "chronic sorrow", or the relentless mourning for the idealized child, has been seriously challenged by her research.

Finally, Marsha Seltzer's and my research on aging families caring for an adult child with retardation at home has yielded some quite unanticipated findings. Specifically, we have found considerably more evidence in support of the "family adaptation hypothesis"--namely that families adjust and adapt to almost anything over time--than for the "wear and tear hypothesis"--namely, the hypothesis that over time, family resources are depleted by stressful situations.

These results do not mean that we have underestimated the "shock" of learning one's child has a lifelong disability or the special challenges that mental retardation poses for families. It does mean, however, that we may have underestimated the

resiliency of families to cope with unexpected events, both initially and over time. They also call into question whether our typical measures of family adaptation--parenting stress, depression, feelings of competence--are, in fact, the most important windows or indicators of how parents individually and families collectively manifest the effects of their unique experiences.

The second issue I'd like to raise is that we have gotten far more sophisticated and perceptive about the multidimensional mechanisms that account for variation in how families respond to mental retardation. There are quite active programs of research around the country that are investigating the role of social support networks, coping strategies, personal beliefs or interpretations, the use and effects of concrete services, etc. as predictors of differences in family and parental adaptation. These aspects of individuals and families are analogous to the famous "black box" in experimental research--that amalgam of forces that cannot be precisely described but which is credited with semi-miraculous results.

There are some attempts to pull together the influence of these different "mechanisms" and to specify how they interact with each other to account for differences in parental and family adaptation. Frey, Greenberg, and Fewell published a paper in 1989 that was notable for its analysis of the differential effect of social support, coping strategies, and personal belief systems on mothers' and fathers' psychological distress and family

adjustment. Orr, Cameron, and Day published a paper in 1991 that used path analytic techniques to support a reformulation of McCubbin and Patterson's widely tested ABCX model of stress and coping. My point is that there is a lot of empirical testing of various models for explaining variation in family adaptation. We have a better handle on what parents and families do in the face of adversity or stress. What we need, however, are better theories about why these "mechanisms"--such as social support, coping styles, external resources, etc.--work as they do, and under what conditions.

The third issue I want to raise relates to our timeframes for research. We know far more about how parents and families react, cope, link to services, find resources, and feel about their children with retardation during the first five years of these childrens' lives than we do about what happens during the next 40 or 50 years. The absence of lifespan research on families caring for a member with a lifelong disability is striking. This problem exists for us in this field, as well as in other fields, such as families caring for a member with mental illness, chronic medical problems, etc. While our questions about family adaptation are inherently longitudinal, we tend to approach them using cross-sectional snapshots. We then try and generalize our findings from one cohort of families--most often volunteer samples, rather than probability samples--to other families at different stages of the family life course.

We must be extremely careful to acknowledge the boundaries

of our knowledge. This is most poignantly illustrated by the often gloom and doom predictions that some professionals still give families about the negative life-time consequences of retardation to themselves, their other children, and their family circumstances. We simply cannot infer that difficulties experienced in one stage of life will result in comparable or greater difficulties in another. Listen to what one mother, in her 70s, told us in response to a question about the positive and negative experiences she's had:

> I guess I would say that now, being seventy years old, I look at a young person who is faced with a child with retardation. If they're afraid to keep the child at home, I'd like to tell them that you get all the help you need, and you get some kind of inner strength to go ahead and put up with days that are bad.

My last point about the thrust of family research over the last 10 years is one that is becoming increasingly noted. Namely, the vast majority of research on families with a member with retardation is conducted using the mother as the primary family informant. And, I should add, these mothers are usually white, and most commonly, middle class. There has been a slow trickle of reports comparing the experiences of mothers and fathers of children with mental retardation.

The results, not surprisingly, indicate both important

similarities and differences. For example, it appears that satisfying social support networks may be particularly effective buffers of stress for mothers. For fathers, on the other hand, feeling that their families were emotionally cohesive and adaptable was a much more powerful buffer of stress. Several studies have also indicated that fathers' relationships with their disabled child is much more stressful in comparison to mothers' relationships, at least during the early childhood period. These studies contain important implications for service provision--which is so often focused primarily on mothers--and for our understanding of the family adaptation process. Rebecca Fewell has been active in examining the influence of the fathers' perspectives and reactions to their child with retardation on the mothers' subsequent adjustment. Thus, the cross-over effects of individual family members' adjustment supports the theory that families operate as a system, where the influences on individual adjustment are complex and mutually interdependent.

We clearly need to acknowledge that the family is greater than just the mother. While this is hardly news, from a research perspective, broadening our definition of a family to include multiple members requires rethinking and expanding our statistical models and considerable work on theoretical models that will help sort out the complex data that needs to be collected.

My final thought about family research is that we need to appreciate better what Marsha Seltzer and Carol Ryff at the

University of Wisconsin have called the "giving and the getting" of family members. They note that "to identify what new parents get from their parental experiences requires outcome measures that go considerably beyond the monitoring of strains and burdens, into the measurement of meaning, fulfillment, purpose in life, and personal growth." I'll end with another quote from a mother in her late 60s, which hints at these more elusive dimensions of giving and getting:

> It all depends on how you look at the situation. There could be two people living in the same house--one could be happy, one miserable. I look at this as my lot in life and I did it and I still do it. He's made a greater person out of me. I've learned a lot from him. He's given me a wonderful outlook on life. Of course, we all wish our children would be normal. There's no question about that, but I'm not going to sit back and say, "Oh, why is he like that?" I'm just going to take off and go. And that's what I did."

Thank you.